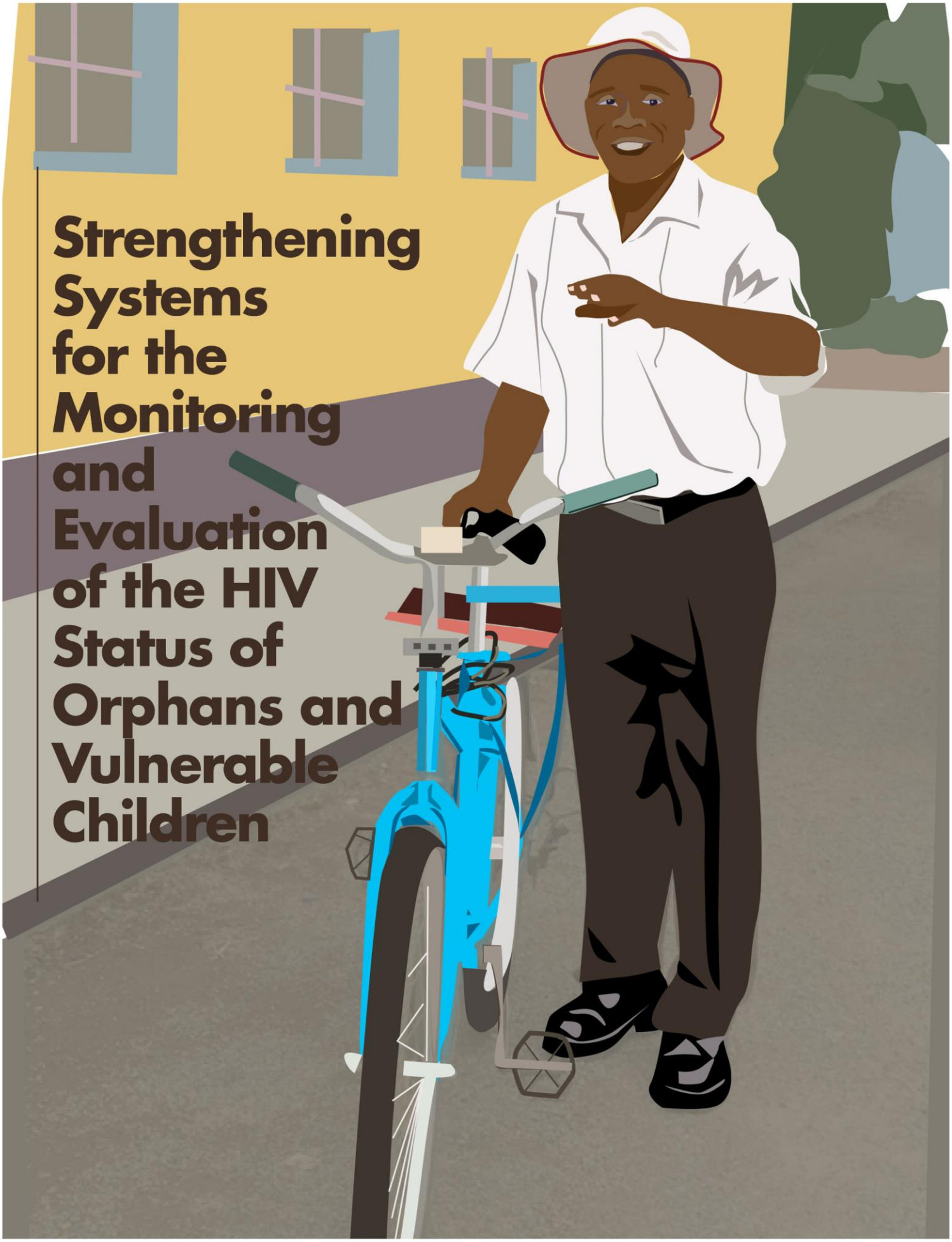

Strengthening Systems for the Monitoring and Evaluation of the HIV Status of Orphans and Vulnerable Children

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MEASURE Evaluation

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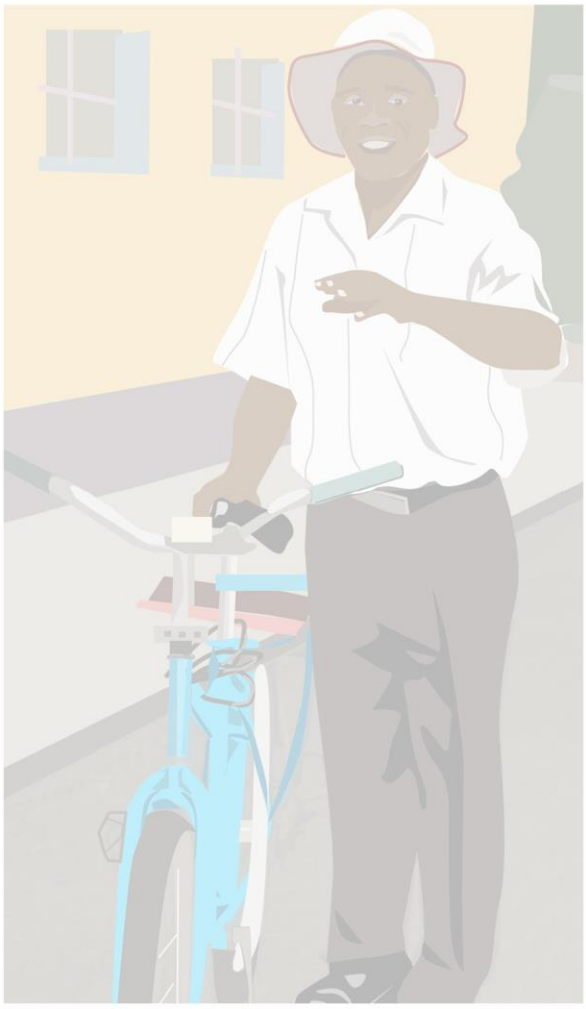

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CONTENTS

ABBREVIATIONS

ART	antiretroviral therapy
CBO	community-based organization
IP	implementing partner
M&E	monitoring and evaluation
MER	Monitoring, Evaluation, and Reporting
MIS	management information system
OVC	orphans and vulnerable children
PEPFAR	United States President's Emergency Plan for AIDS Relief
USAID	United States Agency for International Development

INTRODUCTION

In fiscal year 2017, the United States President's Emergency Plan for AIDS Relief (PEPFAR) introduced a new Monitoring, Evaluation, and Reporting (MER) indicator to collect information on the HIV status of orphans and vulnerable children (OVC). This was done to help gauge the contributions of OVC to the 90-90-90 goals.[1] The new indicator is called OVC_HIVSTAT. The United States Agency for International Development (USAID)- and PEPFAR-funded MEASURE Evaluation conducted a mixed methods study in three countries to collect qualitative data about the monitoring and evaluation (M&E) systems in place for the collection, management, and use of OVC_HIVSTAT data. Performance, data quality, and contextual factors were considered when choosing the three countries for the in-depth study. The countries selected were Côte d'Ivoire, South Africa, and Zimbabwe. Six implementing partners (IPs) across the three countries were visited between November 2017 and February 2018; 32 qualitative interviews were conducted with IP staff and more than 60 community workers participated in workshops on data collection related to HIV risk assessment. MEASURE Evaluation collected and reviewed HIV risk assessments, indicator reference sheets, and standard operating procedures from each IP. Transcripts and notes were analyzed, and preliminary findings were disseminated during a global webinar for the six OVC IPs and their stakeholders on March 14, 2018.

This summary report describes the challenges that the IPs are facing. For example, several OVC programs visited have been slow to adopt the rationale for universal HIV risk assessment as a prerequisite for testing. Although a range of implementation strategies were observed, stigma related to asking questions about HIV risk often prevents community workers from conducting formal HIV risk assessments inside the households. The data collection forms were often problematic, poorly understood by community workers, and open to multiple interpretations by data entry clerks. The guardians of newly detected HIV-positive children were reluctant to report the test results to the community workers. Moreover, once the HIV test results were reported, weak data management protocols contributed to inconsistent documentation of the results. Last, OVC programs faced challenges reporting updated antiretroviral therapy (ART) retention status at regular intervals.

Our analysis of these challenges led to a series of recommendations both for USAID missions and IPs to strengthen M&E systems related to the collection, management, and use of OVC_HIVSTAT data. Many of the recommendations have already been incorporated in the Monitoring, Evaluation, and Reporting Guidance (version 2.3): Orphans and Vulnerable Children, which was released in October 2018. MEASURE Evaluation also developed a set of job aids to support the use of the OVC_HIVSTAT indicator, which are included in Appendix A of this report.

[1] The global 90-90-90 goals state that, by 2020, 90 percent of those with HIV will have been diagnosed, 90 percent of those diagnosed will be on sustained antiretroviral therapy (ART), and all those on ART will be virally suppressed (http://www.unaids.org/en/90%E2%80%9390%E2%80%9390_publications). More recently, these goals have shifted to 95-95-95 by 2030 (http://www.pedaids.org/2014/11/20/unaids-issues-new-fast-track-strategy-to-end-aids-by-2030/).

CHALLENGES

Reluctance to Apply Universal Risk Assessment as a Prerequisite for HIV Testing

The rationale for HIV screening as a means to focus HIV testing and counseling services on those OVC who are determined to be most at risk for HIV infection was not fully embraced by all OVC programs. Certain countries have established a policy of universal testing for all OVC, whereas other IPs remain primarily committed to increasing HIV testing yield. In the first scenario, success is measured in terms of the "proportion of OVC with HIV positive or negative test results." Consequently, these programs often include "negative HIV test result" as a graduation criterion, which means that even those OVC not at immediate risk for HIV are being tested. For those programs focused on increasing HIV testing yield, success is defined as the "proportion of OVC tested with positive results." These programs are performing contact tracing of the sexual partners of HIV-positive beneficiaries without routinely assessing all OVC for HIV risk. These programs have not fully accepted the dual mandate: (1) HIV risk assessment should be a prerequisite before testing; and (2) HIV risk assessments should be conducted on all OVC with unknown HIV status.

Stigma Related to Asking Questions About HIV Risk

OVC programs employed a range of strategies for collecting HIV risk assessment data because many perceived the risk assessment questions to be too sensitive to ask openly during enrollment. Some programs encouraged community workers to gather HIV risk factors informally while in the households and to return to the office to complete the data collection form afterwards. In these situations, where the community workers were not conducting an interview with the data collection form in hand, they may have skipped questions and may have problems recalling the answers later. Other programs conducted desk reviews of existing case files to extract information about risk factors that had been previously collected rather than applying an HIV risk assessment approach. This resulted in delays between the determination of "at risk" and referring the OVC for HIV testing. Specific training on how to implement the HIV risk assessment in households was weak or lacking, although other training programs on voluntary counseling and testing were prevalent.

Multiple Interpretations of HIV Risk Factors Possible

Community workers were sometimes confused about how to complete the HIV risk assessment data collection form. Community workers were instructed to ask multiple questions and determine whether the child was at risk based on some combination of those risk factors. For example, a data collection form included the instruction: "If the answer to 3 or more questions is yes, then refer for testing." For those community workers with low education levels, this type of mathematical formula was challenging. Several data collection tools reviewed also did not have a field clearly labeled to indicate whether the child was "At Risk/Test Required" or "Not at Risk/Test Not Required." In these situations, the data entry clerk was often left to interpret the risk assessment answers, which also led to multiple interpretations of the same form.

Inconsistent Documentation of New HIV Test Results

Despite confirmation from testing facilities that an HIV test had been completed, community workers faced challenges recording the test results on the data collection form. Although HIV-positive children were provided community-based case management, the documentation of the new HIV-positive test results was often not done because of confidentiality concerns. Data entry clerks were asked to review multiple case management tools to

identify new positive test results. Moreover, because a negative HIV test result would not always trigger enhanced case management, negative test results were sometimes not recorded anywhere. Last, even when the HIV test results were recorded on paper, inconsistent policies existed as to how and where to update the management information system (MIS) database.

Disconnect Between Case Management of HIV-Positive OVC and M&E Systems

Challenges were observed related to documenting updates to HIV treatment status. Although the IPs had strong protocols for community-based management of HIV-positive children, there was a breakdown on the M&E side. Treatment status has often been interpreted as the initial linkage to ART and, therefore, is typically collected on the original enrollment form and entered only once in the MIS database. Current treatment status, which should ideally track ART retention, is not being updated in the MIS database at regular intervals. (See Job Aid #3 OVC_HIVSTAT Flow Chart in Appendix A for information about the regularity of HIV ART status assessment.)

RECOMMENDATIONS

Adopt New Indicator to Measure the Implementation of HIV Risk Assessment

We recommend using the current PEPFAR Data for Accountability, Transparency and Impact (DATIM) OVC_HIVSTAT disaggregates to calculate a new outcome indicator that measures how successfully programs are assessing the risk of "HIV status unknown," referring those who are found to be at risk for testing, and subsequently facilitating the self-reporting of new test results. This outcome indicator, "proportion of OVC with known HIV status or for whom test is not required," measures the ability of OVC programs to simultaneously achieve the objectives of: (1) ensuring that children for whom HIV status is unknown are risk assessed; (2) referring children who are at risk for HIV testing; and (3) completing HIV testing for those who are referred and facilitating the disclosure of those results.

The coverage aspect of this indicator ensures that the HIV risk assessment is universally applied. This indicator will measure the ability of programs to work with the guardians of children for whom HIV status is either missing or for whom the guardian reported that the HIV status of the child was unknown to conduct an HIV risk assessment. The completion aspect of this indicator ensures that once a child is determined to be at risk for HIV infection, he/she is referred for HIV testing, the test is completed, and the guardian reports the new test result to the community worker. Successful programs will see a reduction in the number who are reported in DATIM as "HIV unknown," regardless of the reason.

As this outcome indicator is adopted, we expect to see "HIV unknown" decrease whereas "HIV positive," "HIV negative," and "HIV unknown – Test Not Required" will increase. As HIV risk assessment processes are strengthened and M&E systems become more robust, a target of "90% of OVC with known HIV status or for whom test is not required" is recommended. (See Job Aid #2 in Appendix A for an overview of the OVC_HIVSTAT Logic Model and its indicators.)

Integrate HIV Risk Assessment In Regular Household Visits

MER 2.3: Implementation of the HIV risk assessment should be integrated in case management and ongoing case monitoring and should not be conducted separately, if possible.

We recommend that IPs train community workers to conduct HIV risk assessments in the household setting. Community workers should be coached to ask multiple probing questions in the local language to obtain answers to potentially sensitive questions. Community workers should be expected to hold the questionnaire in hand and to record the answers to each question in real time. The data collection tool can be generically labelled "Health Status Assessment" in an effort to minimize the stigma associated with HIV. Consent for testing should be requested as soon as a child is determined to be at risk for HIV. This standardized approach to data collection will enhance the reliability of the data and contribute to the timely linkage of at risk OVC to testing services. The MER Guidance (version 2.3) also recommends the integration of HIV risk assessment in case management, when possible.

Strengthen Training on the HIV Risk Assessment Process

The IPs should develop specific training materials on how to conduct the HIV risk assessment. By ensuring that community workers understand the different pathways for HIV transmission, they will be able to ask probing questions that are culturally appropriate when engaging with the guardians or adolescents. We recommend that the IPs develop role plays to explore different risk factor scenarios. Community workers should be trained on

how to document conflicting information and accurately assess the risk of HIV infection. It is also important that the community workers learn how to complete the form correctly to ease the burden on the data entry clerk when he or she transfers the data to the MIS database.

Simplify the Structure of the HIV Risk Assessment

Although we are not providing technical guidance on specific risk assessment questions, we recommend that only risk factors that require testing be used, i.e., if the answer to any one risk assessment question is yes, testing is recommended. If any single risk factor is met, then the child would be referred for HIV testing. We advise against asking community workers to determine risk status based on a mathematical formula, such as: "Is the sum of response values greater than or equal to six? If yes, then refer for testing."

Clarify the Outcome of the HIV Risk Assessment

We recommend that specific fields be added to the HIV risk assessment data collection form to improve the reliability of the OVC_HIVSTAT data reported via DATIM. After asking each risk question, the community worker should check one of two boxes: (1) "At Risk –Test Required" or (2) "Not at Risk – Test Not Required."

Enhance HIV Test Referral Tracking

Specific fields should be added to the HIV risk assessment data collection form to strengthen the linkage between the assessment and referral processes. After determining that an OVC is at risk for HIV infection, the community worker should refer the child for testing and complete the field, (1) "Date referral for HIV testing made." After the community worker receives confirmation from the health facility that testing has been completed, the community worker should complete the field, (2) "Date HIV testing completed." By including these fields on the HIV risk assessment data collection form, community workers can improve the linkage of those OVC who are at risk to testing services. Alternatively, separate data collection forms can be developed to capture this information. Regardless of where these data are collected, we recommend that the "proportion of OVC at risk for HIV infection who have been referred for testing" and the "proportion of HIV referrals that have been completed" are calculated for the purposes of internal performance management. (See Job Aid #1 in Appendix A for an overview of the HIV Risk Assessment Cascade.)

Strengthen Procedures for the Documentation of New HIV Test Results

Specific fields should be added to the HIV risk assessment data collection form to strengthen the linkage between referral completion and disclosure of new HIV test results to the community worker. After learning that an OVC has completed an HIV test, the community worker should elicit the results and complete the field, (1) "Date negative HIV test results reported" or (2) "Date positive HIV test results reported." By including these fields on the HIV risk assessment data collection form, community workers may improve their ability to document new test results of those OVC who have completed an HIV test and link them to the appropriate follow-up services. Alternatively, separate data collection forms may be developed to capture this information. Regardless of where the data are collected, we recommend that new positive and negative test results be systematically recorded and reported via DATIM because it will impact the calculation of the indicator, "proportion of OVC with known HIV status or for whom a test is not required."

Track the Timeliness of HIV Treatment Updates

Specific fields should be added to the HIV risk assessment data collection form to prompt the verification of ART status at regular intervals. During each household visit, the community worker should track the guardian's self-reported treatment status of the child, defined as "all HIV-positive children or adolescents in the household who are currently on antiretroviral treatment." This self-reported ART status captures both the initial linkage to ART and retention in ART. We recommend clarifying where this information is recorded and ensuring that it is transcribed in the MIS at every six-month reporting period. We also recommend calculating the "proportion of HIV-positive OVC with updated treatment status" for internal performance management to track the timeliness with which these data are being updated.

Analyze and Use Data Collected

We recommend that the IPs use their DATIM submission to calculate outcome indicators and to collect additional data in their MIS to calculate internal performance monitoring indicators. The analyses can be used to provide feedback to community-based organizations (CBOs) on their performance on a regular basis. Once the IPs can provide reliable data for these indicators, they should articulate performance targets, discuss results in data review meetings, and address low performance by conducting supportive supervision and enhanced training. Through the regular analysis of data, the IPs will improve the linkage among risk assessment, testing, and treatment. (See Job Aid #2 in Appendix A for an overview of the OVC-HIVSTAT Logic Model.)

Timeframe to Complete the HIV Risk Assessment Cascade

As soon as an OVC with unknown HIV status is enrolled in a program, the community worker should assess his/her risk for HIV infection, and if he/she is at risk, refer the child for HIV testing, support testing, and the disclosure of results. Ideally, the HIV risk assessment cascade (from enrollment to documentation of the new test results) should be completed in three months. The IPs that ensure the timeliness of the HIV risk assessment cascade will perform well on the outcome indicator, "percentage of OVC with HIV status known or test not required based on risk assessment."

Timeliness of Reassessments

Rather than routinely performing an HIV risk assessment on all children, the OVC_HIVSTAT Flow Chart is provided to guide the process (Job Aid #3 in Appendix A). We recommend that community workers stay alert to a change in the risk profile, which includes sexual activity or sexual abuse. If a community worker suspects that an OVC has either become sexually active or is being sexually abused, he/she should reapply the HIV risk assessment form. In other words, an OVC who has been previously assessed and determined to be "HIV unknown – test not required" or who reported an HIV negative test result more than six months earlier should be reassessed.

CONCLUSION

Many of the challenges the IPs visited during this in-depth study face as they roll out HIV risk assessment can be attributed to the disconnect among case management practices, the data collection forms, and database design. The IPs updated their data collection tools without investing in training for the community workers and overhauling their MIS databases. The rationale for conducting an HIV risk assessment of all OVC has not been fully understood, leading to uneven implementation in different countries.

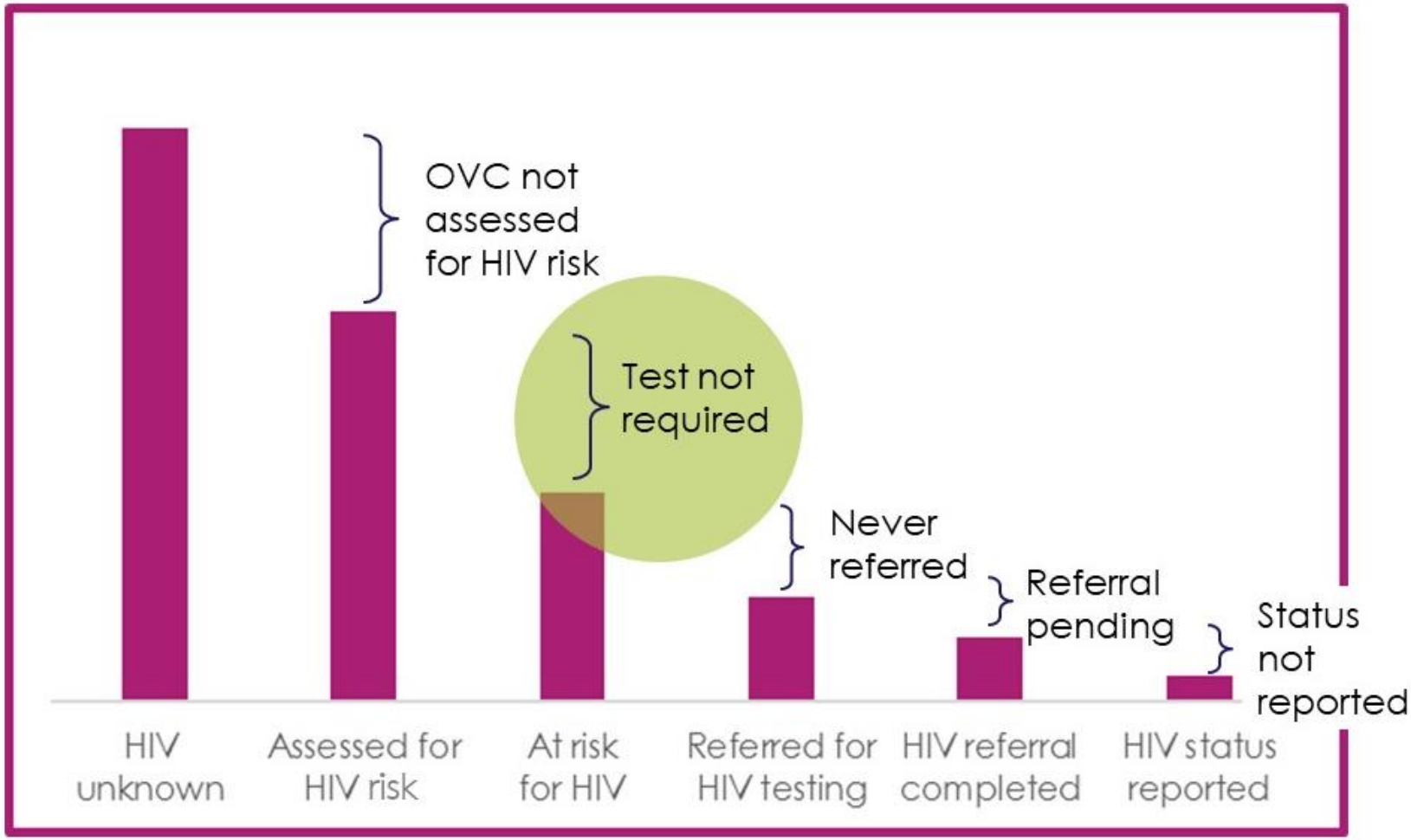
This activity has contributed to two important clarifications: (1) the formula for the calculation of the outcome indicator, "percentage of OVC with a known HIV status or for whom a test is not required"; and (2) the definition of "HIV positive OVC currently on ART" to include both the linkage to ART and retention in ART. MEASURE Evaluation has developed an HIV Risk Assessment Prototype that provides a structure for the data collection tool, thereby enabling the collection of high-quality data on OVC risk factors. This tool will be disseminated widely via the MEASURE Evaluation website. Technical assistance is planned for the IPs who participated in this study to strengthen their M&E systems and to improve the collection, analysis, and use of OVC_HIVSTAT data.

Because these OVC_HIVSTAT recommendations have been incorporated in the recent OVC MER Guidance (version 2.3), expectations are being clarified and target setting can become more robust. We are optimistic that the regular analysis and feedback on OVC_HIVSTAT indicators will strengthen the linkage among HIV risk assessment, testing, and treatment services for OVC populations, contributing to the overall attainment of the global 95-95-95 goals.

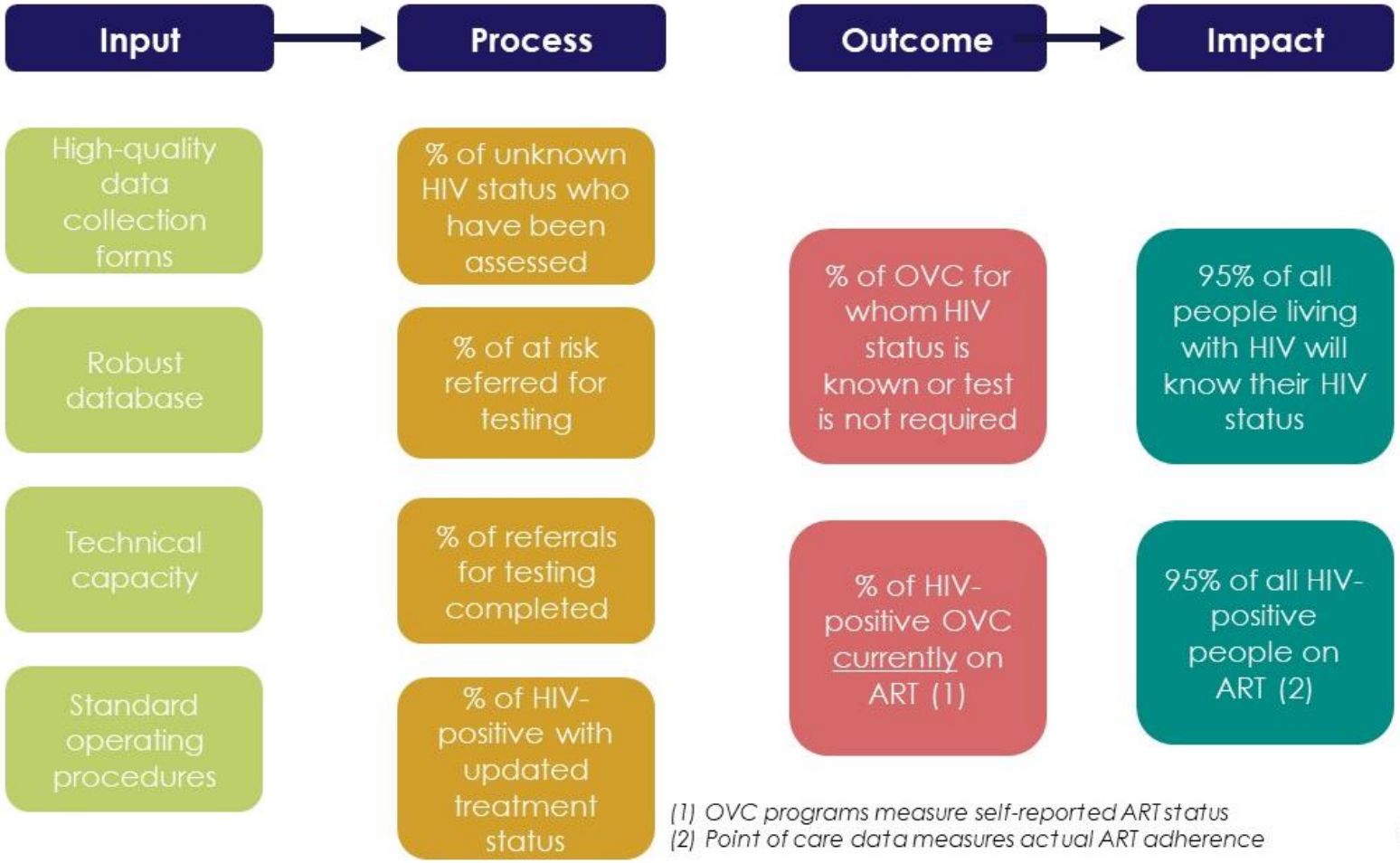
APPENDIX. JOB AIDS

1. HIV Risk Assessment Cascade

2.



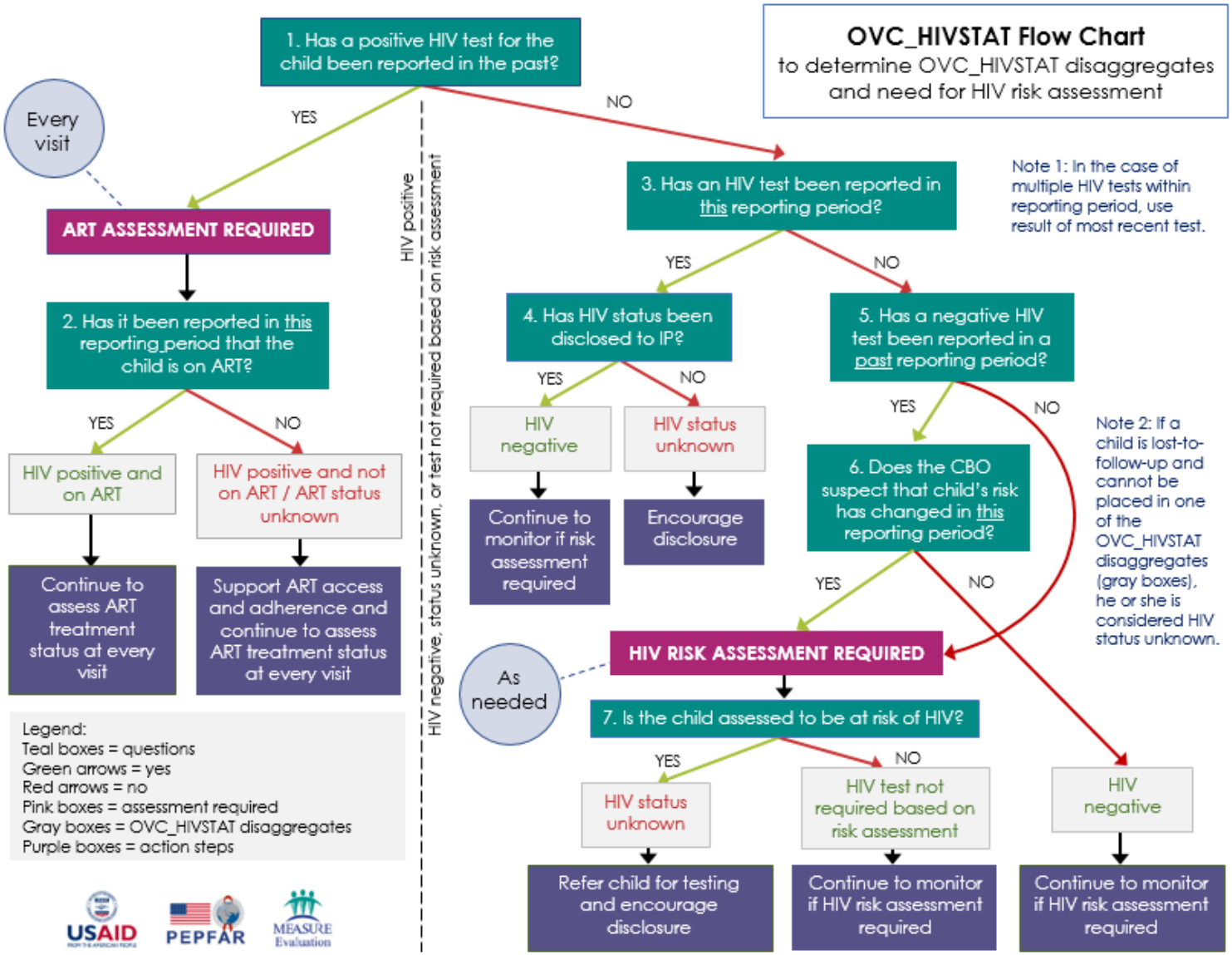
2. OVC_HIVSTAT Logic Model



(1) OVC programs measure self-reported ART status
(2) Point of care data measures actual ART adherence

1

3. OVC_HIVSTAT Flow Chart



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